

PEDIATRIC PROVIDER RESEARCH RESULTS – TELEPHONE SURVEY

1. What is your profession/job?

Profession/job	<u>Surveys conducted</u>
Case Manager	3
Public Health	3
Special Education	2
Speech Therapist	2
Social Worker	2
Community Resource Coordinator	3
Occupational Therapist	2
Physical Therapist	1
Family Practice	2
Psychologist	3
Human Services professional	2
Medical Equipment	2
Psychiatrist	2
Pediatrician	2
Insurance/Payers	2
Clinical Coordinator	2
Directors of inpatient pediatric. Departments	2
Audiologist	<u>3</u>
	TOTAL: 40

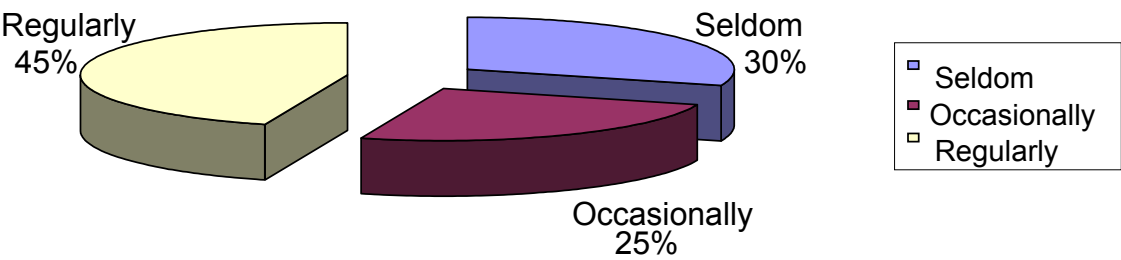
2. In what North Dakota city/town is your office located?

City
Minot – 4
Fargo – 6
Bismarck – 5
Lisbon
Valley City – 2
Portland
Grafton
Dickinson -3
Devils Lake
Garrison
Cooperstown
Jamestown – 3
Grand Forks – 5
Wishek
Hettinger
Williston – 3
Carrington

Total: 40

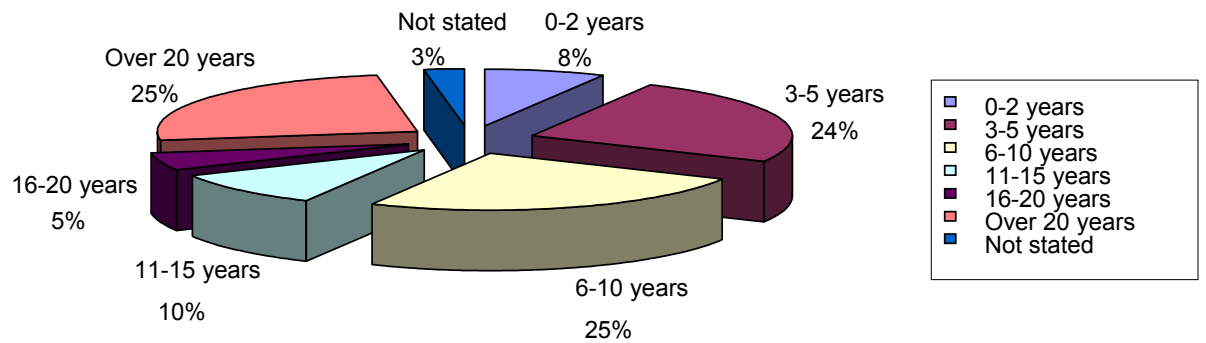
3. To what degree does your job require you to work with children with special health care needs and their families?

	N	%
Seldom	12	30.0%
Occasionally	10	25.0%
Regularly	18	45.0%
TOTAL	40	100%



4. For how many years have you provided professional services in North Dakota to children with special health care needs and their families?

	N	%
0-2 years	3	7.70%
3-5 years	10	25.60%
6-10 years	10	25.60%
11-15 years	4	10.30%
16-20 years	2	5.20%
Over 20 years	10	25.60%
TOTAL	39	100%

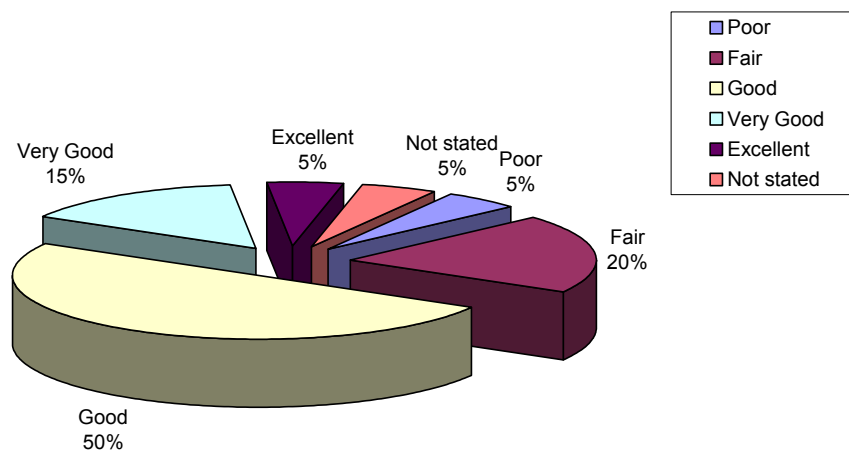


5. Please answer either “yes” or “no” as to whether or not you or your organization typically provides services to children with such conditions.

	Yes	%	No	%	
A chronic illness or health condition	31	86.1%	5	13.9%	100%
A developmental or physical disability	33	91.7%	3	8.3%	100%
An emotional or behavioral condition	27	75.0%	9	25.0%	100%
TOTAL			36		

6. How would you rate the overall availability of resources in your community to meet the needs of children with chronic physical, developmental, behavioral, or emotional conditions and their families (as defined above).

	N	%
Poor	2	5%
Fair	8	20%
Good	20	50%
Very Good	6	15%
Excellent	2	5%
Not stated	2	5%
TOTAL	40	100%



Comments:

*-Good-however, some obvious gaps about emotional and behavioral
-also gaps in those that require skilled nursing around the clock*

*-Good, but would be nice if there was a list of services available to hospital workers
-would like the OB dept. to know where to send parents for conditions and contact information*

7. Is there anything that you think keeps children with special health care needs and their families in your community from accessing needed services?

- Not that I can think of (2)*
- No comment (2)*
- Resource limits on some things like medicals and severe chronic illnesses*
- Medical insurance limits –sometimes claims are denied (3)*
- Co-pays and recipient liabilities*
- Limitation of population*
- Lack of knowledge and support in getting involved (7)*
- Financial reasons (9)*
 - family falls in the middle income bracket*
 - social economic status*
 - funding help to find qualified providers*
- Stigmatism with developmentally disabled*
- Financial resources for kids with emotional disabilities*
- Lack of coordination between similar providers*
- Support groups for families*
- Lots of hoops to jump through and families are not willing or able to do that*
- Legislative limits to appropriate money – can't get everything they want*
- Children with special health care needs are not always identified*
- More education about what is "Special Needs"*
- Availability of services – providers, parents and communities need to know what community and state resources are available and how to access (14)*
- Bad cases will get help, medium cases fall through the cracks because of access problem*
- Distance – service providers are not in rural areas - must transport out to Fargo, Jamestown, and Bismarck (9)*
- In rural areas, a child may wait up to 2 months to see a counselor because provider in town is too busy and lack of availability when needed-this is too long*
- A rural troubled family has less chance to be seen, when in fact they are in higher need*
- Lack of multidisciplinary clinics*
- Referrals are not always correct; some parents think the school can do it all*
- Parents get frustrated and find out things word-of-mouth*
- Need a stronger referral base at the physician's end*
- Tell parents it is Ok to get another opinion or supplemental health*
- Psychiatric problems with themselves*
- Parents with personality*

8. After each statement, please tell me whether you agree or disagree with the statement.

a. In general, children with special health care needs and their families lack awareness about available health care services.

	N	%
Agree	30	76.9%
Disagree	9	23.1%
TOTAL	39	100%

Comments:

-agree – more of a problem in outreach areas, cities have a better grasp
-agree – but better awareness now

b. In general, there exists a lack of adequate public or private health insurance coverage for children with special health care needs.

	N	%
Agree	17	45.9%
Disagree	20	54.1%
TOTAL	37	100%

Comments:

-disagree – usually coverage, but hard to get that coverage
-disagree – I have seen a very nice change
-disagree – most are medical assistance, Blue Cross Blue Shield Insurance clients are seen more regularly
-disagree – medical assistance limitations are causing problems for families with high needs

c. In general, children with special health care needs and their families have a lack of knowledge about how to access the health system.

	N	%
Agree	33	82.5%
Disagree	7	17.5%
TOTAL	40	100%

Comments:

-disagree – but a lot of people are not told enough

-agree – medical – it is up to them, mental – people don't know who to talk to or where to go

d. In general, there exists a lack of respite services or other support services for families of children with special health care needs.

	N	%
Agree	29	74.4%
Disagree	10	25.6%
TOTAL	39	100%

Comments:

-disagree – services are available, but not always staffing

-disagree – the older the children get, the less quality of care they receive

-agree – respite available, but only a certain number of people can access it, many more could use it

-sometimes agree – we have a respite system set up, but not always enough staff for the respite system to go around

9. The following is a list of statements relating to the delivery of services for children with special health care needs and their families. Once again, please tell me whether you agree or disagree with the statement.

a. In general, there exists a fragmentation of services as it relates to children with special health care needs.

	N	%
Agree	29	72.5%
Disagree	11	27.5%
TOTAL	40	100%

Comments:

-disagree – school speech services are fragmented

-agree – because of being in a rural area, certain services are not available on a regular basis – we have hearing services only once a month, special needs are not being met, psychological needs services only twice a month

b. In general, there exists a lack of multidisciplinary clinics as it relates to children with special health care needs.

	N	%
Agree	26	66.7%
Disagree	13	33.3%
TOTAL	39	100%

Comments:

-disagree – there are clinics in Grand Forks and Fargo, but they are too far away, the reservation can access their clinic, non-native Americans have a hard time accessing services

c. In general, there exists a lack of a coordinated funding system as it relates to children with special health care needs.

	N	%
Agree	31	81.6%
Disagree	7	18.4%
TOTAL	38	100%

Comments:

- agree – must go to a variety of places for funding*
- agree – money is not what the community always wants to go for*

d. In general, there exists a lack of public information about community and state resources as it relates to children with special health care needs.

	N	%
Agree	35	89.7%
Disagree	4	10.3%
TOTAL	39	100%

Comments:

- agree – the general public doesn't know where to find it*
- agree – we don't know what is available*
- agree – but getting better*
- disagree – we should spend money on services and salaries for new hires, not advertising; we need a professional in the community that would get information out about services, but first of all we need services here to get the word out, we are a small community, so news travels fast*

10. What, if any, services are lacking in your community and should be made available in order to provide comprehensive care for children with special health care needs and their families?

- Don't know (3)
- We have all the services we need here in Fargo
- Hettinger has all that they can have in their community; our kids are referred if needed to Bismarck and maybe even Dickinson
- Gap in services from age 3 and up – behavioral and special health care coordination
- Early intervention services
- Specialty pediatric care- pulmonary, peds. Rehab, ped. Surgery, ped. Development Dr.
- Wrap around
- More organization and comprehensiveness
- Case management (3)
- Respite services and difficulty of finding good respite care staff (10)
- Speech therapy
- Nutrition clinic in Bismarck
 - many of these children are failing to grow and there is a need to have a nutrition clinic to address their needs
- Summer programming – therapies are not available for children during the summer
- Emotional support and discussion groups for parents and families (4)
- Multidisciplinary treatment centers (2)
- Center for children's mental health
- Center for treatments and evaluation of pervasive developmental disabilities for childhood obesity
- Daycare services willing to take special needs children so it does not always have to be a one-on-one setting – working parents need a break (4)
- Behavioral health
- Need help in placing high school age kids for work-related experiences
- Specialized care in rural areas – mentally ill (4)
- Money for mentally handicapped
- High school graduates move away from rural areas because of limited resources
- Head Start limited to certain income level and certain number of kids – we could easily double that number
- Direct psychological services
- More involvement with kids
- Coordination of services (8)
 - One facility or person to coordinate regions services (5 of 8)
- Coordinated funding system (2)
- Financial help to find qualified providers (3)
- Jumping through hoops and complicated financial support leads patients to give up
- Public education and information about community and state resources (8)
 - who to go to for help and what they provide
 - need information to give to clients on where to go for help
- Greater outreach so families do not have to travel (4)
- Better referral process for special health care needs

- More screenings that are regular, free, educational and held at schools (2)*
- People think the only route to take is social services and pride keeps them sometimes from going there*
- Psychiatric help for kids under 18 is hard to access*

11. What role(s) do you believe the North Dakota Department of Human Services, Children's Special Health Services Unit, should fulfill in serving the needs of children with chronic health conditions and their families?

- No opinion*
- Continue to do what they do*
- Education - Make families and public aware (3)*
- The Overseer*
- Advocates*
- Need a contact person and location within each community (3)*
- Resource specialist training and physician training*
- Provide information and resources (6)*
 - have a list of resources available and give to providers*
- Human Services has worked really hard, 10 years ago it was a problem*
- Money should go to services for children*
- Summer programming*
- Equipment issues (schools already cover some, but then cannot use those in the community)*
- Services are fragmented throughout the state (2)*
 - Funding for respite comes from one area while another service's funding comes from another part of the state – not working well together*
- Need one single case manager that would cover a variety of disciplines*
- Whatever gets marketed there needs to be funding to follow and families get a product that is helpful to them*
- Assessment, assurance and lack of duplication*
- Provide collaboration of efforts in multidisciplinary approach (2)*
- Coordination for kids in rural settings*
- Provision of services*
- Take a leadership role in evaluating the needs and looking at what is out there to help coordinate the programs*
- Develop or encourage providers to provide respite or daycare*
- Awareness to families of where kids can go (2)*
- More variety of residential placements for cognitive care where the kid is in a safe environment*
- Provide adequate funding for programs and services (2)*
 - should cover complete cost*
- Case management (26)*
- Building awareness and linking families to available services (32)*
- Sponsorship of multi-disciplinary clinics (20)*
 - in rural settings (2)*
- Grants (24)*
- Payment of care for eligible patients and families (27)*
- Partnering/Coordination/Collaboration with other organizations (30)*
 - schools and homes (2)*
- Assessing needs and surveying health care providers (dentists, optometrists)*
- Insurance for hearing aids*
- Limited ongoing relationships with medical services*

12. If you could make only one change relative to improving care in your community for children with special health care needs and their families, what would it be?

- Technology provided for kids is limited to Medicaid dollar amount – Kids need the best quality we can deliver
- Develop a brochure that clearly establishes which children qualify and what are they entitled to receive under these services
- Information for providers and clients via a newsletter or something of that nature to inform
- One place to get information and not be intimidated
 - most families don't get information until they are forced to
- Improve delivery of support services in natural environments
- More community services
- Better case management with improved coverage and expanded course of treatment (2)
- One contact person that can concentrate on just children with special health care needs and their families (6)
 - information about resources that can educate parents about available resources
 - coordinate the care between all providers involved, all payment services involved and the school system (2)
- Centralized services under one umbrella
- Coordination and integration providers
- Easier financial support
- Better follow through coordination
 - often parents are minimally responsible
- Knowledge that families are not alone and that help is available – support groups (2)
- Encourage collaboration between hospitals and individual providers, schools and community based programs, etc. (2)
- More outreach programs to rural areas
- Continuity of services and equipment all year long
- Respite-Daycare
- Respite care for behavioral and health problems (2)
- Better networking between all providers
 - Children are our best resource and we need to do things for them!
- Increase access to transportation so can readily and easily access services to the community (2)
- Recognizing reimbursement in state funding in the area of Occupational Therapy
- If the provider was reimbursed at a level to cover the cost of care – the limit to the number of visits is a good thing – this may open up more funds
- Schools shouldn't be funded by medical dollars
- Send a kid to Human Services center and be seen within a week for counseling and have availability of services and support
- More rural resources (medical) in specialty care so they don't have to travel (6)
- More services available for low-income families
- Resource awareness to physicians – more open ended dialog with medical services
- Overall easier access and resource awareness from health professionals as to the services that are offered in our community (2)

13. Do you have any additional recommendations relative to improving services in your community for children with special health care needs and their families?

-No (25)

-Training on specific medical and emotional issues – specific to certain cases

-State is doing a great job in giving back to children

-MR or mentally ill students need to have more money for assisted living –need apartment money for these kids – lack of funding

-Need Case managers to be helpful and coordinate services and keep the public informed

-Need Case managers with appropriate/directive contact, less focus on “requirements” of their job

-Communication between those involved

-Support groups